bcac breast cancer aotearoa coalition

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Submission on Pae Ora Amendment Bill from Breast Cancer Aotearoa Coalition: Sections 68 – 71, Pharmac

16 August 2025

Breast Cancer Aotearoa Coalition (BCAC) has interacted with Pharmac since 2005, seeking access to evidence-based pharmaceuticals for New Zealanders diagnosed with breast cancer. We have experienced Pharmac as an insulated and opaque organisation focused primarily on cost constraints rather than one that strives to provide a best practice internationally accepted standard of care for the population it serves.

It is evident from the Letter of Expectations to Pharmac (2025) from Associate Minister of Health (Pharmac) Hon. David Seymour that the Government seeks to reset Pharmac to deliver more medicines, improve organisational efficiency and develop productive partnerships within the health sector. Pharmac's statutory objectives and functions were written over 30 years ago and inserted unchanged into the Pae Ora Act (2022). We believe refreshed statutory objectives and functions are a vital element of the Pharmac Reset Programme as flagged by Hon David Seymour. The current revision of Pae Ora provides an excellent opportunity to make changes that will set Pharmac on a course to becoming a modern, world-class health technology assessment (HTA) organisation.

Our recommendations for revised objectives and functions follow.

Recommendation 1: Pharmac Objectives and Functions (S68 and S69)

Remove "*and from within the amount of funding provided*" from Section 68 (1) (a) and remove "*within the amount of funding provided to it and*" from Section 69 (2) of the Pae Ora Act.

Pharmac's statutory Objectives requirement, Section 68 (1) (a) of the Pae Ora legislation directs Pharmac "to secure for eligible people in need of pharmaceuticals, the best health outcomes that are reasonably achievable from pharmaceutical treatment **and from within the amount of funding provided**". Its statutory Functions requirement, Section 69 (2) of the Act, requires Pharmac to "perform its functions **within the amount of funding provided to it** and in accordance with its statement of intent (including the

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statement of forecast service performance) and (subject to section 66) any directions given under the Crown Entities Act 2004.

Section 54 of the Crown Entities Act (2004) requires crown entities to operate in a financially responsible manner, making the explicit direction to "spend within funding provided" redundant. Pharmac was established in 1993 to limit Government spending on pharmaceuticals. As noted above, its original statutory requirements were inserted unchanged into the Pae Ora Act 2022, despite submissions that revision was long overdue and amendment should await the findings of the Independent Review of Pharmac 2022.

A primary focus on minimal investment in medicines has become deeply embedded in Pharmac's culture over its 32 years of operation. This has prevented Pharmac from evolving into a modern HTA organisation able to embrace innovation and deliver the benefits of modern medicines to New Zealanders. This view is echoed in the Report from the Independent Review of Pharmac, which states that Pharmac's current statutory objective of securing best health outcomes "from within the amount of funding provided" to be too narrowly focused. The White Paper from the Valuing Life Parliamentary Summit 2024 also notes that the current objectives have resulted in Pharmac focusing on cost, distorting decision-making and leading to sub-optimal outcomes for patients. It suggests an amendment to shift focus to outcomes, recognition of the role and value of investment in medicines, inclusion of societal benefit and better integration into the wider health system.

We submit that removal of these "within funding provided" elements are an essential tool in promoting a shift in Pharmac's culture, thinking and practices, in accordance with Hon. David Seymour's Letters of Expectations for Pharmac 2024 and 2025. This would enable a shift in focus from the current approach of rationing inadequate resources, towards striving to deliver benefits to patients, consumers and society through the provision of pharmaceuticals.

An example of a modern innovative, patient-focused HTA system is provided by the UK's National Institute for Health and Care Excellence (NICE). NICE provides guidance of the National Health Service and wider health care system, aiming to get the best care to people fast, while ensuring value for the taxpayer. In its 2021 5-year strategy NICE articulated their commitment:

- to be "dynamic, collaborative, excellent, innovative, agile and flexible"
- to undertake "rapid, robust, responsive technology assessment"
- to be "world-leading in technologies and medicines, to implement innovation fast, with innovation at the heart of patient care"
- to "make more treatments available, with most assessments of medicines and technologies leading to a positive outcome"
- to be "focused on patient benefit"
- "to adopt gene therapies and CAR-T for cancer"
- to produce "dynamic, living guideline recommendations with uptake to provide maximum benefit"

- “to provide guidance on drugs, diagnostics, digital health, machine-learning enabled devices and ensure rapid access to effective, innovative medicines”.

NICE sees itself as an enabler of market access, a broker of the price for medicines and technologies via the UK’s Cancer Drugs Fund and Innovative Medicines Fund. They see collaboration with industry as a key element and are open to offers to amend value propositions to get medicines and technologies over the line faster. They aim to have significant user input on guidelines, to ensure these are developed through a robust, open, transparent process and available on different platforms and to fit into pathways of care, useful as tools for individuals. They want their guidance “to be used, not to sit on shelves gathering dust”. The NICE Accelerated Access Collaborative has funding and a mandate to ensure uptake of guidance. They plan to tackle inequalities “front and centre” and aim to determine where the biggest impacts can be achieved (public health, clinical, social needs etc). They will use more “real world” evidence, not just randomised controlled clinical trials to find evidence of small differences for small populations. They will “ensure patients are embedded in conversations, on committees, and will be engaged and listening”. They aim to be “trusted, respected and responsive to meet local, national and global need”.

NICE provides an excellent model for a reformed Pharmac.

Recommendation 2: Pharmac Functions (S69)

Update and expand Pharmac’s Functions in Section 69 to align with Hon. David Seymour’s Letter of Expectations 2025 and meet the expectations of patients/consumers and other stakeholders

Associate Minister Seymour makes it clear in his 2025 Letter of Expectations that Pharmac must embrace innovation and optimisation in its processes as well as building productive partnerships and improving organisational culture. The need for a deep reset of these areas was also expressed through the Independent Pharmac Review Report (2022), the Valuing Life Parliamentary Summit White Paper (2024) and the Independent Consumer Engagement Report (2025).

We suggest Pharmac’s functions be expanded to define a broader, more efficient, collaborative and connected role by adding the following objectives and functions to Pharmac’s statutory functions:

- To undertake efficient, timely assessment and decision processes, to provide timely access to internationally agreed standards of treatment;
- To proactively communicate, collaborate with and seek input from stakeholders, including clinicians, patient and consumer representatives and pharmaceutical companies, in assessment and decision processes;
- To transparently benchmark New Zealand’s medicines access against other OECD countries and international guidelines;
- To assess the beneficial fiscal impacts and broader societal non-health outcomes of funding medicines and medical devices; and

- To scan short and long-term horizons to prepare for the timely uptake of innovative pharmaceuticals and medical devices.

Recommendation 3: Pharmac to consult (S70)

Remove "*when it considers appropriate to do so*" from Section 70

Consultation on matters affecting people should be a requirement for Pharmac when it performs its functions. The current wording of the statutory objective only requires Pharmac to consult when it considers appropriate. Removal of that phrase would clarify that consultation with those who may be affected by decisions is an integral part of Pharmac's role.

This amendment is not intended to force Pharmac to consult on trivial matters and leaves reasonable discretion within clause 70 (a) directing Pharmac to "consult on matters that relate to the management of pharmaceutical expenditure with any sections of the public, groups, or individuals that, in the view of Pharmac, may be affected by decisions on those matters;".

Recommendation 4: Pharmac advisory committees (S71)

Amend Section 71 (b) describing a consumer advisory committee explicitly to include "*patient representative*"

Pharmac has to date unilaterally appointed people to its Consumer Advisory Committees (CAC) without seeking input or nominations from the patient groups directly affected by its decisions. It has taken the view that everyone is a consumer who may need a medicine and could perform the role of representing others. Patients affected by Pharmac's decisions have never felt connected to or represented by CAC. It is clear from the Independent Consumer Engagement Workshop Report (2025) that there is a "credibility and trust gap" in patient/consumer engagement. To reset the relationship between patient communities and Pharmac, genuine patient representation from within patient communities is needed in Pharmac. Pharmac's recently formed Consumer and Patient Working Group was built on a different model, being formed from nominations within patient representative groups. This is a welcome first step in establishing genuine patient and consumer representation to contribute to policy and operational elements of Pharmac's Reset Programme and ongoing operations.

To reflect an improved approach to consumer/patient representation, the wording of Section 71 (b) should be amended to refer to "a Consumer **and Patient Representative** Advisory Committee to provide input from a consumer **and** patient point of view"

Ngā mihi

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